

Grant memo

Supporting Self-Determination with Integrity

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Main Entry: **in-teg-ri-ty**

Etymology: Middle English *integrite*, from Middle French & Latin; Middle French *intégrité*, from Latin *integritat-*, *integritas*, from *integr-*, *integer* entire

Date: 14th century

1 : firm adherence to a code of especially moral or artistic values : **INCORRUPTIBILITY**

2 : an unimpaired condition : **SOUNDNESS**

3 : the quality or state of being complete or undivided : **COMPLETENESS**

An Evolving Pattern Language

The movement towards Self-Determination signals a major advance in understanding and practice in 'disability services'. As we celebrate this advance, it might be an especially important time to remember our history and consider what we will carry into the future.

For 200 years, the language of *asylum, protection and special treatment* supported a largely unchallenged pattern of segregation and institutionalization of people with disabilities. For 200 years, we reflexively and systematically stripped people away from the context of family and community life and confined them in segregated settings. Then in the mid 1960's, Burton Blatt and other advocates brought us face to face with the suffering engendered by the institutional 'solution.'

In the field of mental health, driven by a portrayal of institutions as anathema, lured by the prospect of cost containment, and encouraged by the promise of new psychotropic drugs, the overly simplistic language of 'deinstitutionalization' contributed to a pattern of abandonment that haunts us to this day. In the field of developmental disabilities, early attempts at 'deinstitutionalization' were implemented using a service pattern that has sometimes been described as "breaking pieces off of the institution and dropping them into the stage setting of the community in the form of segregated programs."

In the early 1970's, Wolf Wolfensberger, Ed Roberts, and other leaders brought us face to face with the impoverishment of these solutions. The new 'pattern languages' of Independent Living and Normalization (now Social Role Valorization) began to emerge, and for two decades helped to shape our perceptions and refine our practices. As they struggled with the limitations of segregated 'community' programs, parents and allied professionals in the field of developmental disabilities began to envision new directions and began leading the way towards inclusive education, supported employment, family support, and innovative inclusive housing options.

In the 1980's and 90's, pioneers such as Jack Pearpoint and Marsha Forest, John McKnight, John McGee, Herb Lovett, Judith Snow, John O'Brien, Marc Gold, Jean Vanier and others began creating pattern languages that were richer, more adaptive and more complete. *'Circles of support', inclusion, diversity, gifts and contributions, personal futures planning, mobilizing community capacity, invitation, companionship, community-building, hospitality, citizen advocacy, self-advocacy, covenant relationships,*

life-sharing, Gentle Teaching, and asset-based community development all became part of a new working language of allied professionals, men and women with disabilities, family members, and advocates.

As the field moved forward with an enhanced language and a richer vision, people began to discover and forge new *structures* that facilitated collaboration, invited new forms of social engagement, and reversed some long-standing patterns of control: *'Home of Your Own' initiatives, co-housing, cooperative, and microboard initiatives, independent planning, individualized funding, and self-determination* all took their place in the working language and generated a wide array of experiments and models.

Two Steps Forward, One Step Back

As positive as these developments were, practitioners sometimes made the mistake of leaving behind important elements of the *complete* pattern. We backed ourselves into dead-ends, struggled with confusing terminologies and a lack of definition (think about the confusion over *mainstreaming*), moved forward with single-path solutions, and neglected some important lessons from the past. The complete pattern sometimes became lost in the rush of excitement over new terms, new forms, and new initiatives.

Just as the overly simplistic language of 'deinstitutionalization' failed to convey the importance of building strong patterns of support in the community, the raw language of *independence* and *empowerment* sometimes failed to convey the importance of interdependence, contribution and engagement. In some instances (especially in the field of services to people with developmental disabilities) an overly simplistic approach to *independent living* led to a lack of essential supports and social isolation. Direction and wholeness – integrity – receded.

Self-Determination Out of Context

When we carry parts of the larger pattern implicitly, rather than remembering to make them explicit, we may be making the assumption that these desirable directions will automatically be understood and incorporated into daily practice. This is not always a safe assumption. Being reluctant to 'impose' values or direction, some proponents of Self-Determination may lose sight of the importance of supporting companionship, connection, and contribution.

We are beginning to see some indications that the bare language of Self-Determination – "*autonomy, choice, freedom, and responsibility*" – may fail to convey the importance of engagement, companionship, contribution, and affiliation. On recent occasions we have heard new practitioners define their roles within Self-Determination initiatives as simply "helping people with disabilities do what they want." On the surface, these practitioners seem to be working with the assumption that 'finally having control' is a sufficient precondition for a good life. In practice, we have sometimes seen this translate into personal isolation or into an endless round of disconnected 'consumer activities'.

Self-Determination with Integrity

This doesn't have to be the case. A few months ago, we listened as a service coordinator told the story of a man who had lived a tormented life in an institution. He had gained what Herb Lovett used to call a 'severe reputation' for combativeness and challenging behaviour. Under the auspices of a Self-Determination pilot project, he was now living in his own home with the support of resourceful companions and assistants, was contributing to his community, and he was *happy*.

The combat had ended; but one thing was clear: this didn't just happen by writing a check. Indeed, this young man now had much more power to express his life's direction, and he was enjoying a degree of respect that had long been missing in his life. But the overall direction was something that emerged in the context of collective wisdom, companionship, perspective and encouragement.

Our friend the service coordinator had been this man's champion for many years, and now with the flexibility that was afforded by the Self-Determination project, he could fully offer – as a supportive partner – his creativity, his ability to envision a richer life, his skill at inviting and supporting connections, and his sense of a positive, possible future. Money and self-determination was an important condition, but this man's championing played an important role.

Balancing Respectful Listening and Facilitation

In a recent workshop, a leader asked, "What are the characteristics of a good facilitator?" One participant said, "A good facilitator doesn't control the direction, but she does ask important questions."

John McKnight's pattern for Asset-Based Community Development, PATH and related futures planning processes all involve strategic questioning and engagement. They serve as guides for questioning, listening, commitment building, community building, and effectively conveying a new vision.

In I've Known Rivers: Lives of loss and liberation, Sarah Lawrence-Lightfoot reflects on the role of the listener:

As I listen to these extraordinary women and men tell their life stories, I play many roles. I am a mirror that reflects back their pain, their fears, and their victories. I am also the inquirer who asks the sometimes difficult questions, who searches for evidence and patterns. I am the companion on the journey, bringing my own story to the encounter, making possible an interpretive collaboration. I am the audience who listens, laughs, weeps, and applauds. I am the spider woman spinning their tales. Occasionally, I am a therapist who offers catharsis, support, and challenge, and who keeps track of emotional minefields. Most absorbing to me is the role of the human archaeologist who uncovers the layers of mask and inhibition in search of a more authentic representation of life experience. [Thanks to John O'Brien for bringing this writing to our attention.]

There is *direction* in the listening. The direction comes from our willingness, as Judith Snow suggests, to help 'carry the dream' for someone who is vulnerable. It comes from remembering what constitutes a good life, and as our daughter says, it sometimes involves 'speaking your truth with authority'. It means remembering our history and bringing the *entire* pattern into the dialogue – indicating direction without imposing direction. Working with soundness and completeness.

"No, You Have to Be Working There"

A while ago, we listened to a story told by a mother whose son has a hearing impairment and who also struggles with a significant movement disorder. Hearing about his interest in music, people found it easy to think in terms of his attending community concerts and Friday night jam sessions at a local bookstore.

At the outset, David had difficulty expressing the possibility of a musical vocation, and he had no connections in the music industry that would have made that a foreseeable direction. Employment counselors had assumed that his interest in music had little relevance to his prospects for employment. But a friend in his church congregation *did* have connections in the industry, and saw the possibility that David's interest in music might 'take off' in the direction of employment.

'Self-Determination' alone might not have generated this new direction. The possibility emerged because someone knew David well, understood how much meaning music had for him, and understood the importance of capturing the thread of his interest and moving in the direction of companionship and contribution. David's friend seemed to have an innate sense of what it takes to create a good life. He had the audacity to carry the dream for his friend, and he exercised his own power of invitation. His understanding of the value of moving from 'activity' to connection and contribution led to a richer place.

Now David works for a company that assembles the cable sets for the sound systems at large concerts. Most of the time he works in a small factory, cutting cables and installing terminals. He is fully accepted as 'one of the crew'. At concert time, he helps with the final installation of complex sound systems. David has become part of the working music scene in a large nearby urban centre. Last month, as he was about to leave on a three-day trip to help set up a rock concert in the city, his mother (who was starting to feel like she was missing out on the fun) asked, "Can I come?" Her son signed, "No, Mom, you have to be working there."

Some Final Reflections

As we work to support self-determination, we're walking a tightrope, and not for the first time – remember '*the dignity of risk*'? We need to learn to *create* fruitful conditions without *imposing* conditions, and at the same time to not abandon what we've learned about the value of invitation, connection, contribution and engagement. Supporting self-determination with integrity involves deep listening. It involves vulnerability – an

openness to being changed ourselves. It involves a commitment to honour our agreements, and a rigorous commitment to reflect on our experience.

Self-Determination is a vibrant, essential element in an expanding pattern language – an element that has long been buried under the cloak of control and patronage – but it is not a whole language. Individualized funding and independent planning has added flexibility, respect and excitement to the equation, but ultimately, moving towards a life that has integrity (in the sense of *completeness*) involves being on the journey with allies who can share a larger picture.

The traditional language of the Nisga'a Nation of Northern British Columbia includes at least four separate words for the idea of *encouragement*. Every member of the community is reminded that part of their individual responsibility is to offer all four forms of encouragement to friends and family members. One of the words stands as a reminder of the integrity of family and community life – a call to keep the threads of community woven together. The Nisga'a understand that we 'determine' our paths, but they are also always mindful that we also *discover* our paths in the context of companionship and community.

David and Faye Wetherow live in British Columbia. They share their lives with an adopted daughter who has complex mobility and communication challenges, and have long been involved in innovative service and community development.

In their work with the Association for Community living in Winnipeg, they developed Prairie Housing Cooperative and L'Avenir Cooperative, a family- and consumer-directed service agency. They were involved in some of Canada's first supported employment, individualized funding and personal support projects, and created the first 'micro-boards', now a permanent feature on the North American scene.

As independent teachers and facilitators, they have spent years listening to the experiences, hopes and dreams of families, service workers, public servants and community members. They conduct training and facilitate planning for individuals and families, government and community agencies, First Nations communities, schools, church congregations, parent associations and self-advocacy groups throughout North America.

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